



James “JP” M.  
Hepatitis C Mentor

Hi, I'd like to thank Vertex for having me here today to tell you about my journey with hepatitis C.

I'll never forget the day of my diagnosis. I'd recently gone in for my first physical in years. I wasn't feeling bad, but because it had been so long, I asked my doctor to check me out from top to bottom. When I showed up a few days later to get my results, the doctor walked in with a strange look on her face. I could tell there was bad news coming. “James,” she said, “You’ve got hepatitis C.” “What the hell is hepatitis C?” I wondered. I didn't know anything about it at the time—and my doctor didn't really tell me much. She just told me it was treatable and sent me to see a liver specialist. If the look on her face hadn't already said it, the fact that she was sending me to a specialist was enough to tell me the situation was serious.

A diagnosis like that was the last thing I needed in my life. I was going through a divorce at the time and I had a young son to take care of. I couldn't imagine dealing with a serious disease, too. When I saw the

specialist, he told me he had good news and bad news. The bad news was that I'd probably had hep C for about 20 years. My liver was in rough shape. I had stage 3 cirrhosis. But then he gave me the good news: the hep C was still treatable. That's what I needed to hear. The way I saw it, I just needed to hit this thing head-on.

The reason I was so determined is that when I was growing up in Michigan, I lost my dad to a stroke. I was only 14 at the time and it devastated me. I didn't want to put my son through the same thing. I wanted to be there to teach him right from wrong, to pass along the important lessons I'd learned in life—and I'd learned quite a few.

Back when I was just a kid, I had a bunch of buddies I hung out with all the time. We played sports in the summer and shot pool during the long, cold Michigan winters. Sure, we raced cars and motorcycles, and did a little underage drinking, too—but boys will be boys. It was just something to do.

After high school, I got a job working in a factory—and hated it. A buddy of mine worked in a factory and hated it, too. We decided that if we joined the Marines, we'd end up in California and it'd be pretty cool. This was during the '60s, and we hadn't really given Vietnam much thought. We were 18 anyway—you feel like nothing can hurt you at that age. So we signed up.

Well, if I felt invincible before I went to Vietnam, I didn't come back feeling that way. I felt lucky to make it home alive. Unfortunately, my buddy wasn't

so lucky. Not long after I got home, I had to go to his funeral—oh man, that tore me up.

I spent the next few years doing all kinds of crazy stuff. I rode motorcycles, partied, moved around a lot, and had a hard time holding down a job. But when I turned 27, I got a job on the railroad in Michigan—and for some reason I was able to hold it. I was outside all the time and working with a bunch of cool guys. It hardly felt like work at all. I ended up getting laid off, but a few months later they called me back up and asked if I wanted to go to work on the railroad in Virginia. I told them “sure,” packed up my stuff, and left Michigan for good.

A few years later, I got married. I guess you could say my wife and I had a good run, but the marriage got rocky. I had just started thinking, “I can’t believe I’m gonna’ live my life with you,” when my wife told me she was pregnant. I was 50 years old. I decided to hang in there for a little while longer and make the best of it. But things just got worse and we ended up getting divorced. Fortunately, I got a great son out of the deal.

That’s where life had brought me when I found out I had hep C. Things weren’t exactly easy at the time. But like I said earlier, I wanted to get on treatment as soon as I could. My doctor told me about the pegylated-interferon and ribavirin combo treatment, and his nurse showed me how to do my shots. She told me I should do the injection on Friday so I’d have the side effects over the weekend. But that really didn’t matter for me, because I was a railroad conductor and worked on the weekends. It was tough,

physical work. They told me to take a pain reliever for the fever. The first pegylated-interferon shot was the worst: I had no idea how I would feel. I got chills and sweats and all I could think about was how I could handle taking care of my four-year-old son. I hadn't told anyone about my condition. I was trying to keep it a secret because I was embarrassed about it. When I did tell a guy I worked with, he said, "Man, don't tell anybody you've got that. There's a good chance you might not be able to get it cleaned up." But I felt like hell and knew I was in trouble.

Because I didn't have as much energy to take care of my son, I finally had to tell my ex about it—what a mistake! She told everybody. I felt like I was stripped of my pride. People looked at me differently. I could feel it. They didn't know much about the disease and treated me like I was contagious. After a long six months, I found out I was a non-responder. I felt really bad, like all was lost and I would never get to see my son grow up.

Fortunately, not long after that, my doctor told me about another doctor who specialized in treating hep C and made an appointment for me. When I went for my appointment, I met another man with my same problem. He was going through treatment and doing well. Talking to him made me feel better, like there was hope.

When I saw the liver specialist, he told me about a clinical trial for an investigational hep C drug called telaprevir, which is now called INCIVEK™. I told the doctor I didn't know if I could do it again. The first treatment had been so tough. But he said if I didn't, I probably had about

eight years left to live. That scared the hell out me and I decided I was ready to try it again.

I won't lie to you, being in the clinical study wasn't easy. It turns out I was in the group that had INCIVEK added to the pegylated interferon and ribavirin combo treatment. When the side effects kicked in, I got a rash and lost some hair, but that was nothing. The hard part was the depression. Everything made me cry, even TV commercials. But I was really lucky to have a great doctor and nurse, and my doctor put me on an antidepressant, which really helped. I thank my friends and coworkers for looking out for me, too. I had some bad nights where I should have never gone to work, but they helped me through it all. It's good to have that kind of support. Don't be afraid to ask for help if you need it.

Thanks to all that help and my own determination, I finally made it through treatment. And six months after treatment ended, I found out I'd cleared the virus. That made me feel so good. I was so happy to know I'd be around a little longer to see my son grow up.

Now that treatment is over and I'm cleared, I can take my son to the batting cage. We go sailing on my boat and take nice vacations. I even retired from the railroad and started a successful cab business, which I really enjoy. I'm loving life.

But more than that, I've found a new purpose. When I was asked to be a Hepatitis C Mentor, I realized it was an opportunity to help people who had

shared my experiences. When I first signed up for this program, I had to take a little trip where they taught me about being a Mentor. One day, I called my son and told him I was in Boston. "What are you doing there?" he asked. "I got sick," I said, "and had a chance to be in a clinical trial where I got some medicine that helped me feel better. I'm here to show my appreciation. What do you think of that?" I asked him. "That's cool, dad," he said.

And you know what? It is cool to know that I can be here to let you know that if I can face treatment for hep C, you can too. If you haven't been tested for hep C, get tested. And don't be afraid of treatment. It's hard, but it could be one of the best things you ever do.

Thank you.